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ABSTRACT

This report discusses the outcomes of a study that sought to identify the particular problems Canadian parents caring for children with disabilities face in trying to make the transition to work in terms of their child care arrangements and employment-related factors, and best practices in child care arrangements and employment accommodations. Thirty families were involved in the study through individual interviews and focus groups in Ontario, Alberta, and British Columbia. Findings indicate there are major roadblocks to labor force participation of parents of children with disabilities. While there is a need for additional investment in accessible child care, there is also a need for greater awareness on the part of employers. Flexibility in hours and location of work, recognition of particular needs in benefits packages, and awareness on the part of managers and co-workers was found to be essential. The study also identified a number of factors in the broader policy environment that limit the supports that families need, such as increasing regionalization of services, an ongoing policy bias in favor of institutional supports, disincentives to enter the paid labor force because of inadequate home supports, cutbacks to child care programs, and labor standards legislation. (Contains 59 references.) (CR)

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of

Parents Caring for Children with Disabilities

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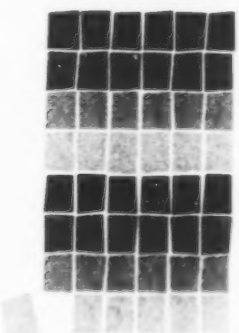

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Introduction

All families have the primary responsibility for caring, nurturing and guiding their children. In Canada, there is also recognition of a collective trust. Communities and governments are expected to play a roll in fulfilling that responsibility. For communities that obligation involves supporting parents to carry out their responsibility by creating healthy and hospitable environments and providing such social and community services as health care, recreation and education. Governments, for their part, are held responsible for ensuring that families have adequate levels of employment income or income support to provide basic food, shelter, clothing, health care and educational opportunities for their children. The 1990 UN *Convention on the Rights of the Child*, to which Canada is a signatory state, sets out the basic human rights to which all children are entitled, and which lays the ground for the exercise of full citizenship (Health and Welfare Canada, 1990).

In 1991, over 7% of children in Canada had some form of disability (Canadian Institute for Child Health, 1994). Most of these children live at home. There is a growing concern that parents of children with disabilities are far less likely to be able to participate in training or employment because of a range of limitations imposed by the reality of caring for a child with a disability. Not the least of these is child care, both in terms of its cost, suitability and availability. However, we do not yet know the scale of the issue in terms of the percentage of Canadian families caring for children with disabilities who are seeking child care or all the particular factors that prevent them from participating in the labour force.

This study contributes to the small but growing body of research attempting to determine key barriers (e.g., child care) facing families who are attempting to balance caring for children with disabilities with paid labour force participation. Two primary objectives guided the study:

1) to identify the particular problems parents caring for children with disabilities face in trying to make the transition to work in terms of their child care arrangements and employment-related factors, and

2) to describe "best practices" in child care arrangements and employment accommodations fostering the labour market participation of parents caring for children with disabilities.

A total of 30 families were involved in the study through individual interviews and focus groups in Ontario, Alberta and British Columbia (10 families in each province). The network of the Canadian Association for Community Living and three of its affiliated provincial Associations for Community Living identified parents willing to participate in focus groups concerning their child care arrangements and employment situation. A detailed interview schedule was designed to guide the interviews. Interviews were conducted with families who did not have the child care arrangements and supports they needed to participate in the labour force, as well as with families whose children's participation in inclusive childcare programs enabled them to be integrated into the labour market. Although the focus of the study was intended to examine child care arrangements critical to parents' labour force participation, what became clear during the course of the research was the importance of supports and accommodations at the workplace itself. Elements and characteristics of employment situations that have enabled families to work while caring for a child with a disability are therefore key findings of the study. It is worth noting that all interviews were conducted with mothers of children with disabilities, although many interviewees spoke of the father's participation in terms of a mutually supportive child care and employment role.

Best practices of employers in supporting parents were identified through parent interviews, a review of policies of selected firms, and interviews with key informants in the area of human resources and employee benefit packages.

Background and Context

Consistent with what is currently a limited body of research (Irwin and Lero, 1997), respondents to this study suggest that parents of children with disabilities are far less likely to be able to participate in training or employment because of the enormous limitations in child care for their children as well as factors related to the work environment itself.

Child care has been on Canada's social policy agenda since the early 1970s and has received considerable public attention largely because of the changing nature of Canadian families. The growing number of mothers with preschoolers who are working outside their homes has accentuated the need for child care services. However, there are only brief periods in the mid- 1980s and early 1990s when federal/provincial and territorial discussion and activity gave rise to the hope that child care would be addressed in a comprehensive and collaborative manner (Friendly, 1997) despite evidence that more and more women are working outside the home. Between 1990 and 1995, numbers of regulated child care spaces dropped in five provinces (Newfoundland, Alberta, Prince Edward Island, Nova Scotia and Manitoba). In a number of provinces (Newfoundland, Saskatchewan, Nova Scotia, New Brunswick and Ontario), regulated child care provided for fewer than 8% of 0–12 year olds (Childcare Resource and Research Unit, 1998).[1] Yet the workforce participation rate for women with children under six years old is up to about 65% (Friendly, 1997) and is expected to continue growing as women exercise their social and economic right to be part of the paid labour force.

Today, organized child care is looking more and more precarious. The federal role in social programs is diminishing. Following the introduction of the Canadian Health and Social Transfer to replace the Canada Assistance Plan, cutbacks were felt across social services. And, along with growing devolution of provincial services to municipalities, there is greater and greater competition for fewer resources.

Because of these trends, parents encounter increasing difficulties in gaining access to community child care for their children. Furthermore, shifting family and community patterns have meant a decline in the extended family and other informal means of support, thereby placing a greater demand on organized child care (Friendly, Rothman, and Oloman,

[1] The Childcare Resource and Resource Unit draws from Status of Daycare in Canada, a publication of Human Resource Development Canada.

1991). These trends are having a serious impact on all Canadian families, and even more so on families in which parents are trying to keep pace while raising children who have disabilities. Nor do concerns about childcare end when a child reaches school age. Indeed, they may intensify as parents struggle with trying to ensure their child's needs are met in the educational system, while at the same time accessing before- and after-school care in an inclusive facility that is preferably in or very close to the school. Parents face yet another obstacle when their disabled children are too old for child care, and they must find non-subsidized informal after-school care.

Families caring for a child with a disability are doubly penalized as a result of additional child care demands they incur, and the difficulties they encounter gaining access to child care. Research data outlines the significance of the problem. In 1991, 12% of children with disabilities aged 0–4 needing child care were refused the service: 35% by licensed facilities, 38% by a care-giver in a child's home and 27% by a care-giver in the care-giver's home. In addition, 9,550 children with disabilities aged 5–14 were neither in school nor were being tutored (Canadian Institute for Children's Health, 1994). Such children would have relied heavily on family members for care-giving support during the day.

Most children with disabilities have needs that require assessments and ongoing appointments with medical personnel (e.g., speech therapists), beyond those required by other children. They also tend to be more vulnerable to medical complications. The time off a parent (usually the mother) needs, decreases her chances of progressing career-wise or of holding down a job at all. Consequently, some parents settle for jobs that allow them the flexibility they need but that are significantly less challenging and less well remunerated than what they would prefer. Alternatively, they drop out of the labour force altogether (Irwin and Lero, 1997).

The well-being of children and their families is directly linked to the social and economic conditions of society. Government fiscal concerns and policies of restraint have contributed to high unemployment rates, job insecurity and declining wages for many Canadians. According to the Canadian Council on Social Development's 1996 report, *The Progress of Canada's Children*, roughly 33% of Canadians worry about losing their jobs and 50% of working mothers are having difficulty balancing work and family responsibilities. For families caring for a child with a disability, these responsibilities and pressures are extensive and inevitably conflict with careers and jobs outside the home. As a result, the economic and labour market mobility of many families are severely hampered.

Parents' Experience in Employment, Education and Training

Interview respondents to this study included parents working in a wide range of occupations in full- and part-time positions, parents who are self-employed, unemployed, on social assistance, and parents involved in education and training programs. In all cases, parents were looking for flexibility in their jobs or training programs so they could provide the required care for their son or daughter with a disability, respond to emergencies, and take the time needed to get children to medical, therapy, and specialist appointments.

Parents' accounts make clear that in most instances the needed flexibility is an elusive feature of the workplace, and its absence often leads to labour market transitions: from full- to part-time work; from professional positions to low-skilled positions requiring less commitment; from employment to unemployment; from employee status to self-employment. The following accounts of parents with different types of attachment to the paid labour force clearly demonstrate that necessary elements such as flexibility, employer awareness, and supports are lacking across the labour market.

Full-Time Skilled Employment

Parents interviewed who were in skilled employment positions include:

- Complaints Investigator with provincial Human Rights Commission,
- Manager of computer operations,
- Office Manager,
- Lab Technician,
- Geophysical Technician in the oil industry,
- Administrator in computer department,
- Child care worker,
- Customer Service Representative at a bank,
- Customs Officer with Revenue Canada, and
- Real Estate Agent.

Many parents spoke of the importance of having a good salary and benefits, such as a medical plan for their financial security. While some do think about "taking a leave and catching their breath," as one parent said, most do not think about quitting because of the difficulty in getting back into the labour force. Even those with a good child care arrangement and supportive spouse tend to use up benefits such as ill-dependent days, sick leave and floater or lieu days to attend to their child's illnesses, appointments and, at times, emergency hospitalization.

Some parents admitted that difficult periods with their children really challenged their ability to be managers and handle work-related pressures associated with managing people, systems, information and budgets, on top of what they were dealing with at home. In addition to the work load itself, which in some cases required overnight travel, some reported that colleagues raised questions concerning their suitability for the position. Mothers find themselves driven, as one woman said, to become a "superwoman."

Although admittedly tired, a few parents spoke passionately about the importance to their self-esteem of undertaking challenging work. One parent stated:

> "I know people with disabled kids who work at the lower end of the work scale, they take a lower-end job, their skills roll downhill, they have less security and less flexibility than I have. They don't realize what they're doing when they choose bad jobs; they can't switch appointments around, they can't close doors, they can't come in later, they don't do themselves any favours and it's very hard to feel good about yourself when any man and his dog can kick you around and blame and criticize you; its very bad for your self-esteem."

Flexibility at the workplace, such as having an office computer at home or being able to take work home, was greater for those working in high-skilled jobs. So were opportunities to take a leave of absence and to move in and out of full-time and part-time work. But flexibility can come at a cost. Obtaining flexibility from co-workers, and building a trusting relationship with them so they can support that flexibility, is critical. For parents, this has meant sharing more details about the complexity of their family life even though they resented having to do so in order that others would understand the critical nature of their demands for flexibility and time away from work.

Part-Time Skilled Employment

Parents in part-time positions included:

- Secretary,
- Supply Teacher,
- Nurse, and
- Computer Technician.

Some parents in positions of responsibility have been able to move from full-time to part-time work within their field . Often this was possible because of their level of skill and their long-time service to a company many would describe as "good employers." The move back and forth to full-time or part-time was often dictated by their ability to access suitable child care; a good arrangement enabled them to work more hours. Often, however, the responsibility that comes with senior positions, and the number of personnel problems that one has to expect, compounded the stress at home. As a result, some parents decided to take a more junior position within the organization, and/or fewer hours so that they could concentrate on their domestic situation. Sometimes the decision was made to resign and leave on good terms rather than be fired if they felt that that was a likely outcome.

For registered nurses who are also parents of children with disabilities, the demands associated with practising nursing in a hospital, which involve 12-hour shifts, days and nights, have been difficult. Some have opted instead to work for companies providing in-home nursing care to people in their homes and children in schools. This arrangement provides flexibility, shorter hours, and less stress. However, some have lamented the stagnation that goes with not using the skills for which they had trained, the isolation, the diminished status that comes with working part-time, the reduction in income and loss of stimulating contact with colleagues. Others have elected to be on-call in a nursing home even though it means irregularity and an early morning call with only one or two hours notice.

Similarly, teachers with long-term contracts often take advantage of the leaves available to them, but after these have expired many find themselves unable to handle the full teaching load with their additional family responsibilities and elect to do supply teaching. Contacts with former employers become useful connections. However, the unpredictability of the calls to teach means not having the lead time to organize child care and

having to turn down offers of work even though the money is attractive. "Saying no because I can't find someone to look after my daughter is something I hate to do because it is so unprofessional," reported one parent, adding that the only time she could be assured of reliable care was on her husband's day off. Rejecting the excessive responsibility but still needing an income, many prefer to take part-time jobs "they can leave at the office," as one parent said.

Education and Training

Educational pursuits of parents who were interviewed include:

- Doctoral studies program,
- Upgrading courses in drafting,
- Accounting courses,
- Rehabilitation Counsellor Programs, and
- Courses on conflict management.

Cutbacks in the health care system have meant job insecurity and layoffs for many workers, including parents who know they are putting themselves at risk by asking for extensive time off to attend appointments and for sick days because of a child's illness. Some parents have responded by going back to college for retraining in fields related to their child's circumstances, an area of personal interest and/or expertise. Even though the decision to attend university or college and not look for work presented an issue financially, one parent described her venture enthusiastically as "a new path with more satisfaction."

Parents taking advanced studies see the importance of pursuing their own interests even as they acknowledge the need to take things on a month by month basis. Studying offers flexibility, but many are forced to interrupt their studies to bring in an income. Others, however, have managed to identify interesting ways of maintaining contact with the academic world. One mother, a doctoral student, described the course she was developing and teaching on the Internet as a teaching assistant. She taught her course, "Family Centred Practices," based on her situation and experience as a consumer, from her home.

Employers recognize valuable employees and will, at times, invest in their further training because they see well-trained employees as an

asset to the company. Most employees respond as long as their child's health is good and their son or daughter can continue to attend child care. However, recurrent health problems play havoc with training, studying and work demands, and may eventually require some time away, even resignation. Many parents, if they have to quit, are keen to leave on good terms so that the employer's door may be open in the future.

Work in the Disability Field

Three parents who were interviewed work in the disability field in positions of:

- Office Manager,
- Provincial government employee, and
- Family Support Worker.

Sometimes parents are approached by other families to take positions in the disability field because of their knowledge about what families go through in advocating for their sons and daughters. Having "been there" gives them confidence that they can handle the work. The office positions are more attractive to some and represent a diversion from the ongoing front-line care they face on a daily basis. For some, this represents a new career path, the former one having been interrupted upon the birth of their child with a disability. It often starts on a part-time or contractual basis with no benefits, but usually provides flexibility and an appreciation of the employee's personal circumstances. Such positions can provide useful information from the service and policy perspective, advocacy initiatives, links with others in the field, professionals and families, and a natural support system for the working parent. As one parent indicated, there is a high level of awareness in the workplace about the situation of her family, and a willingness on the part of her colleagues to step in and help out:

> "I got the job because of my situation — I just fell into it. I never thought of working in the disability field. The information and the knowledge I get are very useful to me, personally. My biggest worry is being able to produce for them. Other parents trust me and provide my support system. Two weekends ago I got a bit of a break when one family invited my daughter to stay with them."

Self-Employed

A couple of parents found that the only way they could obtain the flexibility they needed was to start their own business. One family's decision to start their own printing business was prompted by a denial of the mother's request to return to her former publishing job on a part-time basis after the birth of her daughter. The stress associated with a seven-day week to get the business going was balanced somewhat with not having to account to a boss or to adhere to a rigid work schedule. The greater degree of flexibility meant they were able to enlist the assistance of their extended family for the care giving needed outside of the day care centre's hours.

Low-Skilled Jobs

Parents who identified themselves as having a low-skilled job included the following:

- Seasonal Worker,
- Store Clerk,
- Bingo hall "caller", and
- Baker at donut shop.

The comment by one parent, "I am reliable but my son is not" typifies the argument parents use to explain their decision to find low-skilled jobs. They move from full-time to casual work because this is all they can commit to. They like to be in the adult world, get out of the house, do a few hours work, even if it is at minimum wage, and prefer not to have to worry about day care. The convenience of a job in the neighbourhood is attractive. Some acknowledge the financial risk; others express dreams of going back to school sometime in the future, but, in the meantime, there are too many appointments to keep. As one mother said:

> "I would love to have a real job with fancy clothes and go to work in a nice store, but it's hard to have a real job with a child with a disability because my whole life is spent at doctors."

Unemployed

The decision to take courses that will lead to employment opportunities or employment itself is sometimes abandoned when the pressure becomes too great. One mother described her success in a part-time accounting course and a subsequent job offer. She subsequently quit when her husband was transferred to another province. She found managing two children on her own interfered with her ability to perform efficiently for even a five-hour work day. While she knew she could do the work, and that it would be of good quality, she felt the pressure was too great. She believed that she would "make a mess and no one would be very happy." Not wishing to remain unemployed entirely, she indicated she had just been for an interview at a fast food restaurant and was hoping for a positive outcome.

When parents choose to take a job with less responsibility, they are usually choosing a job where they will have less overall flexibility, and where they may find even fewer accommodations. This in itself can be stressful, without the monetary compensations of a more responsible position.

A considerable number of parents find juggling work and caring for a child with a disability so stressful that they decide that one spouse should stay home full time. Of course, the spouse and the entire family will pay a considerable price for this choice in terms of reduced income, the stress and isolation of staying at home, foregone career opportunities and the compensations that go with them, and the difficulty of re-entering the workforce later in their lives.

Social Assistance

One mother reported that she qualified and was currently receiving child maintenance and social assistance because she was caring for a child with a disability and was unable to work until he was in school full time. As a single parent, she felt she really would not be able to balance her son's needs, his irregular sleep patterns, his illnesses against the demands of a job. "I can't work and stay the long term," she insisted. Despite her years in drafting, she felt unable to focus on a career. Yet, she recognized she was at her most competent point in her life — more focussed and skilled than she had ever been. She expected that the work she would eventually find would keep her busy physically, but not tax her mentally.

Another mother on social assistance described her personal struggle to recover from an addiction. A tireless advocate for her son, she took some courses to learn to help other parents going through what she herself faced, including getting her children back from foster care after going through rehabilitation. "Poverty is a hell of a thing to get out of," she commented, wondering whether, in the face of cutbacks, there was really an attempt to get people off the system at all. She, herself, was determined to find the way, if there was one.

Workplace Factors Affecting Employment Status, Opportunity and Experience

A complex set of workplace factors shape the opportunity for parents of children with disabilities to seek and obtain employment, the occupational status they aim for, and a high quality of working life.

Barriers

The research points to a number of barriers in the labour market and the workplace that affect parents' employment status, opportunity and experience.

Unsupportive supervisors

The degree to which supervisors were perceived as supportive or not had a major impact on some parents' ability to hold down their jobs. Many felt their ability to handle their work and domestic situation was questioned and in some cases their very job threatened. This led to requests for transfers, challenges to higher authorities, performance appraisals, and additional stress. Other parents indicated how hard it was to concentrate on their work when made to feel by their supervisor that they were always letting everyone down. As one mother suggested:

> "You get the feeling it's not working for anyone before anyone actually says anything. Sometimes it's better to quit rather than get fired for rotten reasons."

Those who cannot afford to quit learn how to hold their energy in reserve. Although they have the experience and know that their supervisors expect them to go the extra mile as in the past (e.g., taking calls from clients at home), most parents indicated that they no longer feel they have the stamina they once had.

Inconsistent practices

Respondents reported different experiences even within the same organization, depending on the skill and educational level at which they worked. In the experience of one employee working on computer systems "the office was totally flexible." Another employee, at the same company, but working in warehouse shipping and receiving, said there was no flexibility regarding hours, time off for medical appointments for their child, or special leave benefits — every request was met with "take it as your holiday."

Pressure from colleagues

Many parents feel they need to be on guard with their co-workers. Although some colleagues may empathize with what parents caring for a child with a disability might be going through and may even offer to do whatever they can to help, there is a shared feeling about the importance of being vigilant. Some suspect a certain jealousy on the part of their colleagues that they seemed able to "hold it all together." Others sensed resentment because they were not always available. The pressures they felt from their colleagues added to the weight of their responsibility.

The hiring process

The dilemma faced by all parents interviewed for a position is how much of their domestic situation to describe. One parent summed up her experience this way:

> "Last time I was called for an interview it was for a good job, including flexible hours and benefits. But once I said that my husband was away and that I had a child with a disability I could see they were losing interest in my application ... the more I talked the more trouble I got in!"

Telling about the demands of having a child with a disability is not an issue for those who have found their jobs through personal connections. Many worried that not telling their employer in advance meant requests for time off could threaten their job. In some provinces the law states that an employer cannot ask an applicant about their children. While there is no obligation to do so many parents insisted that it was better to be "up front" in the hope of avoiding trouble down the road. From the perspective of parents interviewed for this study, employers tend to be unaware of

how to manage the interviewing and hiring process in a way that: 1) separates family demands from skill and capacity for the job; and, 2) encourages parents to discuss their family situation so that employers can better understand how they can be accommodating.

Inflexible work loads and schedules

The demands of shift work — particularly in hospitals with long hours both day and night, and the rigidity — has forced many parents to leave the profession for which they had trained and worked. Refusals by supervisors to accommodate the needs of parents led them to suspect that their employers were actually glad to see them resign rather than have to be in constant negotiations for time off for child appointments, leaves and illness.

Upgrading/refresher courses

Many parents worry that their absence from the labour market will mean losing touch with developments in their field, requiring re-certification before re-entering, or at least taking upgrading and refresher courses. While they recognize why their professions require this, it nevertheless represents an additional hurdle to their going back to work in terms of cost, pressure and time commitments.

Limited benefits

Parents found that formal benefits, including adequate, extended medical plans and health coverage, significantly helped them manage their work and family responsibilities. Some benefit packages have a discriminatory impact because certain provisions (e.g., some dental plans) exclude coverage for selected disabilities. Many parents lamented the lack of benefits associated with part-time employment.

Inadequate provisions for paid family responsibility leave were commonly cited as a barrier to managing work and family responsibilities. Even though some employers provide paid leave, (e.g., four family related sick days a year), this was deemed vastly insufficient for parents caring for children with complex health conditions. In some situations, paid leave provisions are also allocated for medical appointments, but they do not reflect the actual time required given the range of appointments all parents described.

Loss in benefits and reductions in salary caused by moving from

full-time to part-time work pose critical financial worries for many families. Some parents, fatigued, wish to take a leave of absence, but fear that to do so would jeopardize their jobs.

One parent reported that she had been working 19 years for the same bank. There had been opportunities for mobility and she had moved from full-time teller to assistant manager but began working in a clerical job after her child was born. While that suited her in some ways, working part-time meant losing out on a pension because she would not contribute as a part-time employee.

Many indicated a similar career trajectory, with the accompanying costs. For example, one parent reported:

> "When I was the boss of the office I accumulated seniority and 5 weeks of holidays. In my new secretarial job I qualify for only 2 weeks and I have lost a lot of benefits, too."

A federal government employee tried to claim benefits while on a half-year stress leave only to return to work even more agitated than when she left. The health insurance benefit plan refused to pay her benefits because, as she was still able to care for her child, she was not deemed sick enough to qualify for any benefits. There was even more confusion regarding payments for Employment Insurance and the Canada Pension Plan. Finally, after she wrote several strong letters about the grief she was experiencing, the benefits were approved. This difficulty defeated the purpose of her leave:

> "The whole point of taking that time was to spend time with my daughter and learn about her illness. Then, with all the anxiety, I ended up going to a counsellor who called my boss. At least, I came to work for a boss who understood my situation."

Success Factors

Six key factors make the workplace supportive of parents of children with disabilities. They are:

Supportive Manager/Supervisor

Characteristics of a supportive manager include: someone it was possible to be up front with, who had full knowledge of the challenges facing an employee, and who would try to make the necessary workplace adjustments to enable an employee to maintain his or her job; who would offer a leave instead of accepting a resignation; and who would leave the door open whenever the employee was ready to go back to work, full time or part time.

One manager, who was hiring for a position that required working with children needing extra support, was applauded for viewing positively the fact that the prospective employee had a child with a disability and saw the situation as an added qualification rather than a handicap.

Organization of work

Key aspects of the organization of work that support a parents labour market integration include:

- the extent to which the necessary equipment and tools are made available to the employee in a flexible manner (e.g., having an office computer at home);
- the degree of autonomy and control an individual is able to exercise over his or her work (e.g., having one's own case load; teaching a course electronically from home); and,
- the opportunity to make up time taken off for appointments and to care for an ill child (e.g. working in processing behind the scenes where it is possible to make up lost hours rather than in a front-line customer service position where it is difficult to leave).

Favourable climate

For some employees a favourable climate means being able to close their door on a "bad day" and write reports without having to interact socially; knowing they can trust their office mates to cover for their absences or mistakes from time to time; being allowed to bring their child to work in emergencies; having access to a quiet space for the child to breast feed and sleep; getting recognition and tolerance for the fact that there would be no guarantee that every day would be the same; and having considerate colleagues who also provide adult conversation and stimulation.

Flexibility

Parents identified a number of components that would make for a truly flexible workplace:

- having some control over hours of work;
- being able to schedule meetings, appointments and group sessions when convenient;
- being able to enjoy the benefit package attached to full-time workers;
- being able to accumulate overtime in order to take extra time off as needed;
- working from home;
- knowing it was possible to go immediately to get your child if it became necessary to do so; and,
- having an accommodating educator/trainer who is willing to make adaptations to course assignments and practicums.

Benefits

One of the chief advantages of full-time and, in some cases, part-time work to families caring for children with disabilities is the benefit packages such jobs offer including medical/health and dental plans. However, while some parents indicated that certain therapies are provided on medical plans, it does not take them long to reach the maximum claim allowed. Some disabilities are exempted by insurers. For example, some parents report that certain dental plans do not cover their children with Down syndrome.

Length of service and seniority prove advantageous to some families when it comes to the assignment of shift work, accumulating paid leave time and vacation days. Supportive leave policies have been negotiated in some collective agreements, and/or covered through employers' human resources policies.

Some interviewees recommended that employers provide stress leave for employees who are parents of children with chronic illnesses. With new developments in medical technology, there are higher survival rates of children born with complex health needs. As a result, there are increasing numbers of parents whose children have

such conditions. The changing demographics of disability, together with the societal expectation that children be cared for at home, need to be recognized in contracts and workplace benefits in terms of parental stress and the need for time to alleviate it.

Accommodation by employee

Some parents feel that their success at work is contingent less on the accommodations made by others in their workplace and more on their own personal ability and willingness to be flexible and accommodating to maintain good working relationships. In return for taking time off to attend appointments, they feel they have to be particularly cooperative. This might include working extra shifts to get the day off they need; working a Sunday even though they may have been promised they could take it off; being asked to work late on Friday night at the last minute and feeling they could not refuse.

One parent resented having to tell her co-workers details of her son's disorder so that they would understand her situation:

> "I work on a team of four or five people and it's hard on me if there is tension — so I'm the one who has to do the accommodating. I do enforcement work — I'm a customs officer, I arrest people, there's hostility and tension. If, on top of that, there's tension with the people you work with — it's awful. I'm used to working with a fair amount of stress but, at a minimum, there needs to be a basis of trust and good relationships."

What Some Companies are Doing to Accommodate Parents

If workplaces have been slow in recognizing the difficulties many employees are facing in juggling work and family responsibilities, they have been even slower in recognizing the needs of parents who have children with disabilities. According to Hewitt Associates, a consulting company that specializes in benefits, most companies deal with situations involving parents of children with disabilities on an individual basis, without a policy to guide them. Predictably, this approach results in inconsistent practices within the same organization, and leaves parents very much at the mercy of individual managers who, in the absence of supportive policies, even if sympathetic, may be limited in how much they can do to help. On the other hand, even in companies that have supportive policies, there may be an unwillingness to enforce managers' use of them. Instead, it is often left to the discretion of the individual manager. This can be less than helpful if he or she is not supportive of the employee's needs.

Nonetheless, parents are likely to fare best in companies that have comprehensive and supportive work/life policies. For example, the Bank of Montreal has a work/life policy that includes five areas of flexibility:

Flextime: employees are able to have a flexible work schedule in terms of hours, providing the work gets done.

Flexweek: employees are able to work a compressed work week.

Flexplace: employees are allowed to work out of their homes.

Flexwork: employees are able to work part-time, and not be penalized in terms of seniority and advancement.

Job sharing: employees can share their jobs.

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Best of all, employees are not penalized for making use of these options either in terms of their level of employment, benefits or seniority. From the company's perspective, they do not take employees less seriously who, for example, opt to work part time or job share.

In addition, employees have access to benefit programs that can be increased according to individual need, as well as a special fund — The Sir Vincent Meredith Fund for families suffering hardship due to family illness — which, for example, might help to pay for a modified van or other special need.

Some companies provide on-site child care (e.g. Ontario Hydro), while others assist with finding and paying for child care (e.g., I.B.M.) Others allow family leave days (e.g., four per year), special leave (usually unpaid) or sabbaticals, usually every five years.

While such policies may be helpful to many parents of children with disabilities, for other parents, they will nonetheless fall short of what is really needed. For example, four family leave days may be used up within a month, let alone a year. Nevertheless, these policies are a positive beginning, and need to be recognized, supported and built upon. In general, practices that support parents are likely to work best when they are part of an overall comprehensive policy supporting diversity in the workplace.

How Child Care Arrangements Affect Parental Employment

Opportunities for parents of children with disabilities to participate in employment are limited by two key barriers in child care arrangements, and are enabled by a number of success factors.

Barriers

Lack of access

In searching for a suitable child care program, many parents were surprised at how little was available; how inadequate some programs were in terms of health and safety practices; how unreceptive some centres were to including children with disabilities; the range of excuses they encountered for excluding some children; and the expectation that parents would provide an aide.

In trying to secure access to day care, parents have encountered outright rejection by centres who have focussed negatively on their child's behaviours; two-year waiting lists for integrated centres; segregated child care as the only available option; day care fees they cannot afford; and transportation costs. They have had to secure a diagnosis in order to qualify for a resource/support person to work with their child and, in many cases, devote hours of their own time teaching teachers how to communicate and work with their child.

Inadequate response to need

Lack of child care capable of supporting children with complex medical needs continues to interfere with parents' ability to find and retain employment. Children whose health status is fragile and who are in and out of hospital play havoc with the employment status of their parents. Many parents described "their worst moment" as getting a call at work informing them that they needed to come home immediately because their child was sick, or needed to be rushed to hospital.

Special outings at day care or school represent an extra demand on some parents who, feeling it is too dangerous for their child to participate without one-on-one support, take the day off work every time such an outing is planned.

Some centres' policies stipulate the child can attend only those days when the resource person is working, irrespective of parents' work schedules; in other situations, morning day care is offered at no cost, but families are expected to pay fees in the afternoon. Even though parents may worry about a particular program or arrangement, there are so few resources available that they may choose to ignore their concerns.

Success Factors

Parents pointed to five child-care related factors that have a positive impact on their employment opportunity, status, and experience. They are:

Availability

A critical factor in parents' employment situations is the extent to which a range of child care resources are available to them and that offer their children quality care and supervision. In addition, child care services need to be reliable, affordable and equitably distributed.

Comprehensiveness

Parents require a variety of arrangements, including in-home babysitters, family day home providers, after-school programs or staff before and after school/work, full-time, centre-based child care, combinations of inclusive child care in the morning and Junior Kindergarten in the afternoon. What employers have been able to put into place has a clear impact on parents' own work schedules and choices.

Quality child care

In trying to secure access to day care, parents have encountered excellent inclusive programs in which their child has thrived. Job satisfaction to parents caring for children with disabilities requires knowing that their children are well taken care of, are safe and happy. To most parents this means a stimulating environment with children the same age in an inclusive child care program.

Respite services

In addition to having a child in child care, some parents also need respite care. The extent to which this need is met influences parents' work patterns. For one family, this may mean having a respite worker in the morning (when their child's behaviour is particularly difficult) in order to get ready for work. For another, it provides time to clean the house because as one parent reported:

> "When my life is in disarray, my house reflects that disarray — it's bad for morale and self esteem."

Flexibility

Many parents appreciated the flexibility a family day home provided for child care, especially experienced providers who know how to access additional supports for the children. Parents found this arrangement worked well for children who have weak immune systems or who are at risk of getting infections, but still need to be around other children. Parents often conduct a number of visits to find the right situation. They conduct informal assessments of providers to determine a good match, that is, someone who relates well and is not afraid of their child's condition or of handling a G-Tube, for example. One mother felt lucky because "the caregiver and I felt like sisters" and both families felt like "one big family."

Flexibility results when the facility can be used as a regular or drop-in arrangement, when plans can be adjusted the night before if there is a change in work schedule, or if one parent works on an "on call" basis. Parents identified quality, reliability and stability of the program as important factors. In others, they found someone who had the know-how they were looking for: As one parent put it,

> "She understood FAS (fetal alcohol syndrome) and why the kids both demanded extra attention but also needed proper structure."

One parent indicated that the primary factor enabling her to work was both the transportation company's and the family support worker's (from the local Association for Community Living) willingness to be flexible. In order for her to be able to work her shift, the bus driver picked up her daughter first and dropped her off last when she either could be there herself to meet the bus, or arrange for the family support worker to do so.

Environmental Factors Affecting Parents' Choices in Employment and Child Care

In reviewing both federal and provincial government initiatives in those provinces where this study was conducted (British Columbia, Alberta, and Ontario), a number of key policy factors emerge that affect parents' employment opportunities. Shifts in public policy and inaction on government commitments to invest in child care are severely restricting the employment and child care choices that parents can make. The cost is both unemployment and under-employment of parents caring for children with disabilities.

Changing Federal Role

Responding to a report card on their 1993 election promises, the Federal Liberal Government conceded that despite persistent demands for a publicly funded, national, child care program, their child care commitment remains unfulfilled ($720 million on 150,000 day care spaces). In 1996, the federal government identified child care as a provincial responsibility (Childcare Resource and Research Unit (1997).The impact of this action is felt at the community level by parents who are faced with a lack of affordable and accessible child care programs. The assumption that extended family members can play a supportive role in providing child care for working families does not fit the reality of most people's lives. Some families incur an added financial burden because they choose a child care program primarily to provide stimulation for their child. Yet, they are unable to claim these child care costs for income tax purposes because they are not in paid employment.

One recent initiative of the federal government is a new national child benefit system that came into force in July, 1998. The federal government promised an initial $850 million down payment for the new benefit to incorporate the existing $5.1 billion child tax credit for low-income families and the provincial assistance programs for children. The

Integrated Child benefit aims to put more money in the hands of working families with children earning less that $25 000 a year, and to eliminate anomalies between the working and non-working poor that often make it advantageous to remain on welfare (Revenue Canada,1998). However, researchers point out that the benefit is structured to reduce welfare rolls, not to reduce child poverty. As some provincial governments are at the same time reducing welfare payments for low-income families, children in families on welfare gain no new benefit. The National Council of Welfare estimates that some families will be worse off (Childcare Resource and Research Unit, 1998). Child care representatives have identified the importance of this benefit scheme being complemented by services to assist children of poor families. Poor families are concerned that the benefit is too low to make an appreciable difference.

The Disability Tax Credit (DTC) provides some assistance to families caring for a family member with a disability. The DTC reduces the income tax payable by qualifying persons with disabilities, and is transferable to family members (Revenue Canada, 1996). However, in 1994 eligibility criteria were tightened, and excluded some who had formerly qualified (Multiple Sclerosis Society of Canada, 1996). In addition, many consider the DTC inadequate. Some parent organizations are lobbying for a tax credit system that recognizes the true costs associated with caring for a child with a disability, so that families can acquire the economic stability necessary to provide for them.

Government Restructuring and Regionalisation

In 1993, the Government of Alberta appointed a Commissioner of Services for Children and Families to design "an integrated, more effective, and community-based system of support to children and families." Services have since been redesigned at the regional level under the auspices of Child and Family Services Authorities, and services formerly provided through Handicapped Children's Services have been integrated with many other children's services (Alberta Ministry of Family and Social Services, 1998). During the consultation process many families expressed alarm about the proposed changes to the provincial Handicapped Children's Services Program, which provided funding to families to support their child at home and in the commu-

nity. Most families were receiving services through the latter program when they were interviewed for this study. The program's services were funded fully or partially and included day programs, medications, transportation and respite services. Reimbursement was determined on an individualized basis.

The impact of these changes on families is not yet fully clear, as the transition is still in process. At the time of the interviews, parents were worried that Handicapped Children's Services would be relatively weak when positioned against much bigger programs, including child protection and child welfare services in the inevitable competition for funds. Moreover, they argued that Handicapped Children's Services is not itself a program like those with which it is being grouped, but a benefit to families, a provision that enables them to access other programs.

Despite their wish to see Handicapped Children's Services retained as a separate provincial program, many families had concerns about the program itself, and they identified a number of obstacles parents encountered in accessing the benefits. These include the lack of parental control over the flow of dollars; the fixed annual limit (a month of illness could deplete the funds for the rest of the year); the disincentive to work because expenses not covered by Handicapped Children's Services frequently outran potential wages; the eligibility criteria are based on not working; the predictable and exhausting patterns of application, denial, and appeal; and inconsistency and discretionary decision-making, which have prompted some families to move to different parts of the province where they know the practices are more favourable.

Institutional Bias Against Supports at Home

As long as institutional facilities exist in communities, parents continue to feel they are being held hostage. The only way they can get all the services, specialized supports, and relief they need is to consider placing their child in a long-term care facility. Many families reject this option: to them it is not ethical. They resist the pressure to give up their child and they know the difference between the high daily cost at the institution and the less expensive cost involved in providing supports at home.

In each of the interviews conducted in Ontario, Alberta and British Columbia, families reported receiving supports at home, but many echoed the conclusion that, while the supports are essential, there is not much benefit from working outside the home. Several examples demonstrate their frustration. For example:

- Special Services at Home Program (Ontario):

"I have to pay the worker $9.12/hour but I only make $6.85/hour."

- At Home Program (British Columbia):

"We do get formula, feeding bags, diapers, and medication, but in terms of respite hours, we get $196/month, which, at $12/hour, translates to one-and- a-half-days of care."

- Handicapped Children's Services Program (Alberta):

"The babysitter rate is 7.50/hour, but you also have to pay mileage on top of that, which is not covered."

Cutbacks to Child Care

In Ontario, cuts in spending in recent years have reduced drastically the number of spaces and centres providing child care for working families. Hundreds of licenced centres have closed because of cutbacks in subsidized spaces. The Ontario Coalition for Better Child Care (1998) reports that 9,000 Child Care subsidies have been lost and 71 daycares closed in Toronto alone since 1995. In 1995, the provincial government strongly considered abandoning the subsidy situation that supports 2,800 centres across the province in favour of a voucher system. They backed down due to a public outcry, but by downloading 50% of childcare funding to municipalities in January, 1998, opened the door for municipalities to reduce options of licenced care in favour of more cost-effective unregulated care. Costs for providing supports for children with disabilities have not been included in new cost-sharing arrangement (McQuaig, 1998). Provincial downloading of responsibility for funding and licencing centres to the local governments has resulted in higher user fees for those families receiving child care subsidies.

This erosion has been extended to local school boards that have closed school-based day care programs to make way for increased enrolment in regular programming and because the space they occupy is no longer covered in the new education funding formula. A 1989 program, which made day care centres mandatory in every new school and provided the capital and start-up funds, was reversed in 1995. School boards are no longer required to provide junior kindergarten, because funding has been reduced, and start-up grants are no longer available. In addition, the education act was amended to prohibit education spending on child care. As a result, 22 school boards no longer have junior kindergarten programs, causing communities to lose over 20,000 junior kindergarten spaces (Mathien and Johnson, 1998).

Designated integrated child care programs include children with disabilities on a partial day basis, generally for half-a-day. These programs are licenced to provide specialized programming and a resource teacher for every four children with a disability. Parents using the program in the morning are eligible for an 87% subsidy. However, there is little flexibility in child care programs and policies to accommodate changes in work schedules requiring afternoon care. Changes in work schedules requiring child care until 2:30 p.m., for example, are met with rigid rules and practices: parents have to pay for the whole afternoon, they cannot count on getting a subsidy, and there is no resource worker. Yet, parents have to hold on to their spot or risk losing it.

Supported Child Care Initiative in British Columbia

In 1990, the province of British Columbia began a review of the Special Needs Daycare Program. For four years, government, parents, and community members from across the province worked on a new approach to include children who need extra supports. In December, 1994 the province adopted the new approach and began a transition to the new Supported Child Care Program. According to the British Colombia Ministry for Children and Families (www.mcf.gov.bc.ca), this program is based on the belief that:

- all families should have the same child care choices in their communities;

- some children need extra supports to be included with their peers; and
- child care settings also need supports to successfully include all children.

Supported child care gives parents more flexibility in choosing a centre or pre-school. In the previous system, with special needs day care, certain centres were designated with "special needs spaces" and government would fund them. Now, the dollars are being transferred from the centres to parents in order that a child with extra support needs can go wherever his/her parents choose. Ministry social workers still determine eligibility. Families are required to pay the same basic fee for a child care space paid by all other families (subsidies are available) and the Supported Child Care program pays for the extra support a child needs.

As with any large scale change there are some emerging challenges: centres that received block funding in the past do not want to give up that security, and are resistant to changing their programs; some families and centres fear losing staff with specialized backgrounds and expertise in the changeover; some families fear the cost and their ability to pay; many assert that it is unfair to expect families with children with disabilities to pay the same fees on the grounds that it is necessary to treat families differently for them to enjoy equal benefit.

The Transition from Social Assistance

At the same time as the deterioration in child care is being felt, there have been legislative and policy directions in Ontario and Alberta to get parents who are on social assistance into the paid workforce. This push is evident as welfare dollars are redirected to the new Child Benefit for working-poor parents (to remove incentives for staying on social assistance) and workfare legislation is introduced. Critics point out that these measures result in increased poverty, fragmentation of services, and increased demand for fewer child care spaces (Ontario Coalition for Better Childcare, 1998; Workfare Watch, 1996).

Despite the pressure being exerted on parents on social assistance to enter the paid labour force, the experience of the two mothers

interviewed for this study was one of overall despair that they would ever be able to get all the pieces in place to make the transition to work. The obstacles they identified include cutbacks in childcare, disrespectful treatment at the hands of professionals, and the lack of information about services and supports — a situation summed up by one mother as "having to make a 100 calls to make another 100 calls." Rather than feeling that they could take some risks to get off social assistance because there was some security behind them, one parent said, "we're out there alone to sink or swim" in what appeared to be a very unpredictable future.

Workfare programs for people on social assistance do not account for the extensive arrangements that must be put in place by parents, especially if they are caring for a child with a disability. Parents in this study reported they receive little advance notice of the career training program they are expected to take, and they need to turn up or risk losing their support. Being told to "get your child care in order" does not take into account the fact that child care is unaffordable without a subsidy. Yet a subsidy is granted only after confirmation of work has been received from an employer. The career training program may have a fixed start date, but the community day care may not have a space at that exact time. Even if there were a space, payment would be necessary to secure it. In addition, there would also be the issue of determining and arranging the necessary supports before the child started.

Policies may presume parents are ready to work once their children reach school age, but they do not allow for the possibility that a substantial number of children, regardless of their chronological age, continue to have significant support needs (e.g., related to sleep disturbances, behaviours, physical challenges) that require constant supervision and affect parents' ability to seek and hold employment.

If social assistance policy requires that parents work or enter training programs, then much greater awareness is needed of what the real barriers are, and what is needed in order to facilitate parents joining and remaining in the workforce. This is particularly true of parents of children with disabilities, who seem to be, for the most part, an invisible group in policy deliberations and analysis.

Conclusion

Research that addresses issues of working parents of children with disabilities has generally been quite limited. Such research, including this report and Irwin and Lero's study, has been initiated with the assumption that childcare is the key barrier to these parents gaining access to employment. This focus has perhaps been predicated on the fact that child care, particularly for preschool children, is an issue for nearly all working parents, and therefore it makes sense that it is likely to be an even greater issue for parents of children with disabilities. While access to child care is a significant barrier for parents, as this study confirms, the barriers to employment for these parents go far beyond accessible child care. The particular needs of the child (e.g., medical appointments) and the unpredictability of those needs; the willingness and ability of employers to accommodate the parent (e.g., workplace flexibility); and additional physical and emotional demands of caring for a child with disabilities are some of the other factors that have an impact on a parent's capacity to seek and retain paid employment.

In looking at the issue of childcare, this study initially assumed that child care is an issue for parents when the child is young, and that it diminishes significantly as the child gets older and becomes more independent. However, this tends to be the trajectory of parents whose children do not have disabilities. This trajectory does not necessarily apply to parents of children with disabilities. Indeed, by assuming that it does, we end up with a skewed analysis. The reality is that, for many of these parents, their children's needs for additional supports do not diminish over time. As some parents in this study reported, it may become more difficult to meet the needs of children as they get older. For example, finding and maintaining appropriate educational placements may be even more difficult than finding appropriate child care, and for most parents they will have to do both. What does appear to get reduced or eliminated altogether as children grow older are the child care resources needed to meet their needs. Formal child care ends for children over 10–12 years, and there are no subsidies for child care beyond this age.

If there is little research on working parents with children with disabilities, there is even less on single parents of children with disabilities. They are a neglected group within several research contexts: balancing work and family; employed parents with children with disabilities; and single mothers on social assistance. Because of the lack of attention to this group of parents, we know very little about how they are managing. Two-parent families often juggle the responsibility of caring for a child with a disability by taking turns with child care. The options for single parents are obviously much more limited, unless they have other means of financial and practical support. If parents in two-parent families suffer serious stress and exhaustion from the role of working and caring for a child with disabilities, the challenge for single parents is that much greater, if not insupportable.

This report makes clear that major roadblocks to labour force participation of parents with disabilities exist in the workplace. While there is a need for additional investment in accessible child care, there is also a need for greater awareness on the part of employers about the particular situation of parents with children with disabilities. Flexibility in hours and location of work, recognition of particular needs in benefits packages, and awareness on the part of managers and co-workers are essential. Otherwise, the challenges of caring for a child with a disability will be intensified by exclusion from the paid labour force. This study points to the need for voluntary action on the part of employers, and of unions where collective agreements are negotiated, to make their workplaces more supportive and accommodating. It also points to the need for greater awareness of their obligation to do so.

Finally, this study found that employers may not be able to bring about labour force inclusion for parents caring for children with disabilities all on their own. It identifies a number of factors in the broader policy environment that limit the supports that families need, such as:

- greater federal-provincial cooperation to secure tax and fiscal policies that support families caring for children with disabilities;

- increasing regionalisation of services to people with disabilities, which makes it more difficult, in some cases, to equitably target resources to children with disabilities and their families;
- an ongoing policy bias in favour of institutional supports;
- disincentives to enter the paid labour force because of inadequate home supports;
- labour standards legislation that does not recognize the unique situation and needs of these parents;
- cutbacks to child care programs in some regions; and
- welfare programs' growing emphasis on parents to make the transition from social assistance to paid employment without providing needed supports.

Efforts to create inclusive and supportive child care policies are beginning to take shape in some provinces. This is one part of the equation for making transitions in and through the labour market possible for parents of children with disabilities. The other part is the labour market and workplace itself. Designed primarily for people who can keep private and domestic responsibilities from encroaching on their responsibilities in the paid labour force, the workplace and current public policy is failing those who have responsibilities for children, aging parents needing support, and family members with disabilities. Their needs for support cannot be "held at bay" until the demands of a workday are completed. This study suggests that practical solutions can be found to make workplaces more accommodating and supportive, and that inclusive child care policies are beginning to take shape. To make the real difference, however, a comprehensive policy framework for employment, family support, and child care is urgently needed so that parents of children with disabilities can obtain a quality of working life that supports a secure foundation for their family's well-being.

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